

"Dying with Dignity"

The Rhode Island End of Life

Conference Series Report

Sheldon Whitehouse, Attorney General

Growing up, she could hardly wait for her girlfriend's sleepover party, her first prom, her approaching wedding day. Years later, years that seemed like the blink of an eye, she could hardly wait for her first grandchild to enter the world. And, now, all she can do is wait; wait for the final days of her life to come to an end. And, sadly, if the end is like many others, it will be an end burdened by unnecessary pain and unnecessary and undignified medical procedures.

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THE END OF LIFE CONFERENCE SERIES

Sheldon Whitehouse, Attorney General

The elderly population in the United States increased eleven-fold from 1900 to 1995, as our life expectancy increased from 50 years to 75 years. The fastest growing segment of the elderly population is now persons 85 years of age or older. Clearly, the state of End of Life Care is an issue of increasing importance and concern to all of us.

I recently convened a conference with the Brown University School of Medicine, Rhode Island Medical Society, Rhode Island State Nurses Association, Rhode Island Bar Association, Rhode Island Department of Elderly Affairs, Aging 2000 and the American Association of Retired People. What did we find? Thanks to the participation of eighteen experts, we found that far too many Rhode Islanders are dying in considerable pain, pain that could be prevented. We found that living wills and other legal documents that Rhode Islanders use to protect their dignity and their choices are often ineffective. And we found that there can be solutions to these problems if we work together.

The major areas of concern addressed at the Conference were: minimizing pain, respecting a person's final wishes, discussing increasing health care costs and the legal requirements necessary to express end of life wishes. The following is an overview of some of the information that was shared at our Conference Series.

Pain must be recognized as a real and legitimate healthcare problem: Studies have shown that, while 1 out of 4 people nationwide die in nursing homes, and 83% of nursing home residents experience pain, nearly 30% of those residents receive no form of medication for their pain. Studies have shown that greater than 70% of a terminally ill patient's pain can be relieved with narcotics. Yet, the fear of intractable pain during the dying process continues to be a major concern of dying patients and their families.

Respecting a patient's wishes for end of life care is both an ethical and a legal issue. Rhode Island law provides for two types of advanced directives: the Durable Power of Attorney for Health Care; and a "living will" under the Rights of the Terminally Ill Act. The Comfort One Program, operated by the Rhode Island Department of Health through the Division of Emergency Services, is the only way a terminally ill patient can avoid receiving life-prolonging treatment. While 75% of Rhode Island's nursing home residents complete advanced directives, many families of these residents have reported multiple communications problems about the directives and the choices they made regarding treatment. A hospital's Ethics Committee can be a good resource to patients and their families facing these difficult situations, to help clarify a patient's wishes, improve communication between patient and health care providers, identify ethical principles, and outline options for end of life care.

National health care costs associated with end of life care are startling. 30% of total yearly Medicare expenditures are for people who die within that year. 40% of the total Medicare expenditures in a person's last year occur in the last 30 days of that person's life. Despite the high burden put on the Medicare system for end of life care, 31% of nursing home residents spend most of their savings to pay for long-term treatment. In fact, more than 50% of the costs for long-term care and medications are out-of-pocket expenses for the patients.

Rhode Island General Laws provide that a licensed health care professional who administers, prescribes or dispenses medication to relieve pain, even if the medication hastens or increases the risk of death, does not violate Rhode Island General Laws §11-60-4 unless the medication was knowingly administered, prescribed or dispensed with the intent to cause death. Patients and health care providers alike should be aware of their rights and obligations regarding receiving and providing pain treatment. Further, health care providers should be aware of their legal obligation to respect the wishes of a terminally ill patient regarding the end of life care that he or she will receive. There is legal precedent that a hospital may be liable for negligent failure to honor a patient's wishes, especially a Do Not Resuscitate Code.

The End of Life Conference Series provided an overview of these areas of concern. There is much to be done. One major step is the Rhode Island Partnership to Improve End of Life Care established by Brown University School of Medicine, Center for Gerontology and Research, Aging 2000, and other organizations. Under the direction of Joan Teno, M.D., the Partnership is studying of end of life care in nursing homes and developing educational programs for health care providers. Aging 2000, in conjunction with the Attorney General's Health Care Advocate, has developed a training program for health care providers and an educational guide for the public on planning for end of life care.

I am grateful to the co-sponsors of the Conference and the panelists. The speakers provided key insights into the state of end of life care today and ideas to improve it in the future. An executive summary of each of their presentations can be found in this Report. Together, we hope to improve end of life care in Rhode Island so that our loved ones achieve greater comfort, dignity and control at the end of life.

Sheldon Whitehouse

Attorney General

March 29, 2001

KEY FACTS

PAIN ASSESSMENT AND MANAGEMENT:

A Brown University School of Medicine survey of family members of persons who died in Rhode Island nursing homes in 1997 and 1998 reported that 50% of the decedents experienced pain:

2/3 of the decedents' families rated the pain as severe;

25% of the decedents' families believed more should have been done for their pain¹

Nationally:

70% – 95% of terminally ill patients' pain can be relieved with narcotics.

The major concern of dying patients and their families is the fear of intractable pain during the dying process.¹

83% of nursing home residents experience pain that impairs mobility, causes depression, and diminishes quality of life. ¹

Nearly 30% of nursing homes residents with daily pain were not receiving pain medication of any form. ¹

Among nursing home residents who die, nearly 1 in 4 did not have their pain treated.¹

Fear of prosecution by the prescribing doctor does appear to be a significant factor in limiting dying patients' access to pain treatment.

RESPECTING PATIENT'S WISHES:

Two types of advanced directives are provided for in Rhode Island law: the Durable Power of Attorney for Health Care and the rights of the Terminally Ill Act, sometimes "living will" (R.I. Gen. Laws §§ 23-4.10-1 et seq. and 23-4.11-1 et seq., respectively.)

Nationally, 58% of nursing home residents have signed a health care proxy.⁴ However, in Rhode Island, 75% of nursing home residents have executed documents expressing end of life care treatment wishes. ¹ These forms are usually completed by the patient or family member to be acted upon by doctors, and often do not use relevant medical terms or standards, leading to confusion and misunderstanding.

In Rhode Island, 35% of the families of the nursing home residents who died with an advanced directive, reported two or more communication problems with medical providers, which had they received different information, may have influenced the treatment options. ¹

Do Not Resuscitate ("DNR") requests are more likely with older people. ⁸

Nationally, 70% of deaths are in the over 65 population. ⁸

Lack of long term planning is evident. Nationally, 79% of patients die with DNR codes; 50% of which are authorized just two days before death. 8

Advance directives do not save money, but may reallocate expenses to hospice, SNF, etc.8

58% of Rhode Island patients at the end of life have some limited form of care such as a Do Not Resuscitate (DNR) code. 2

The Comfort One Program, operated by the Rhode Island Department of Health through the Division of Emergency Services, provides a terminally ill patient with the opportunity to register a decision with the Department of Health not to receive life-prolonging treatment. It is the only expression of the patient's wishes that an EMT team is permitted to honor.

Since October, 1993, approximately 2,850 patients have enrolled in the Comfort One Program. 6

The Ethics Committee of a hospital is a multi-disciplinary team consisting of physicians, nurses, hospital staff, ethicists, hospital chaplains, community members, and legal representatives, which seek to determine the right and appropriate course of action with conflict treatment plans.

The Ethics Committee can help clarify patients' wishes, improve communication between patient and health care providers, identify ethical principles, and outline ethical justifiable options for end of life care. 7

THE LAW:

R.I. Gen. Laws § 23-4.10-1 provides for Health Care Power of Attorney. 5

R.I. Gen. Laws § 23-4.11-1 provides for Rights of the Terminally Ill Act, also known as a Living Will. 5

R.I. Gen. Laws § 11-60-4 provides that a licensed health care professional who administers, prescribes, or dispenses medication to relieve pain, even if the medication hastens or increases the risk of death, does not violate the provisions of this factor unless the medication was knowingly administered, prescribed, or dispensed with the intent to cause death.9

There is legal precedent that a hospital may be liable for special damages resulting from negligent failure to honor a DNR code. Anderson v. St. Francis – St. George Hospital, 67 N.E.2d 225 (Ohio 1996).10

NATIONAL HEALTH CARE COSTS:

30% of all Medicare expenditures in any given year, are for people who die in that year.

40% of Medicare expenses occurred in the last 30 days of a patient's life. 8

Medicare expenditures rise with age. 8

28.5% of Medicare subscribers who survive major treatments are over 80 years old and use 30.1% of Medicare expenditure. 8

49.7% of Medicare decedents are under 80 and use 59.9% of Medicare expenditure. 8

3.1% of Medicare decedents had no Medicare expenses. 8

Acute care expenses decline as age and dependence rises. 8

The number of medical/surgical procedures performed on patients decline with age, except joint surgery. 8

5% of the Medicare population used 27% of Medicare's Annual Budget. 8

31% of nursing home residents spend most of their savings to pay for long-term treatment. 8

More than 50% of the costs for long-term care and medications are out of pocket expenses for patients. 8

general:

Nationally:

Between 1900 and 1995, the elderly population increased eleven-fold with the fastest growing segment of elderly persons 85 years of age or older. 1

Life expectancy increased from 50 years to 75 years between 1900 and 1995. 1

1 in 4 persons die in a nursing home. 1

75% of nursing home residents reported that nurses listen to their hopes, fears, and beliefs. 1

Only 44% of nursing home residents had someone speak to them about religious or spiritual concerns and only 15% were referred to religious or spiritual leaders. 1

43% of persons age 65 and older will spend time in a nursing home prior to their death. 1

75% of nursing home residents are female; 46% are greater than 85 years old; 87% are Caucasian; 44% are admitted from a hospital; 32% are admitted from home; and 23% are admitted from other nursing homes. 2

80% of nursing home residents have impaired decision-making and 50% have dementia. 2

96% of nursing home residents need help with bathing and dressing; 62% need help using a wheelchair; 56% using a toilet or a bathroom; and 45% need help eating. 2

30% of patients admitted to nursing homes die within two to six months of their admission. 2

Rhode Island is 1 of the top six states in which people die in nursing homes. 1

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2 David Gifford, M.D., MPH

Kathleen C. Hittner, M.D.

Margaret S. Wacker, R.N., Ph.D.

Nancy Fisher Chudacoff, Esquire

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Thomas A. Bledsoe, M.D.

Peter A. Hollmann, M.D.

9 Russell Sollitto, Assistant Attorney General

10 E. Paul Grimm, Esquire

IMPROVING END OF LIFE CARE

IN RHODE ISLAND

As a result of the End of Life Conference Series, the Department of the Attorney General's Health Care Advocate, in conjunction with Brown University School of Medicine, Center for Gerontology & Community Health and Research and Aging 2000, is working towards improving end of life care in Rhode Island. The following steps are already underway:

To educate the public about memorializing their end of life care wishes so that they may have legal effect, Aging 2000, with the assistance of the Attorney General's Health Care Advocate, published a guide, "Choices and Conversations," discussing end of life care and distributed it in "The Sunday Providence Journal." In addition, the guide is available in physician offices throughout Rhode Island.

Aging 2000 and the Attorney General's Office of Health Care Advocate designed a training program for health care decision making agents or surrogates which is expected to be fully implemented by the Spring, 2001.

The Attorney General proposed 2001 legislation requiring all licensed health care facilities to assess pain on a regular basis and to manage such pain.

The Attorney General proposed 2001 legislation creating an orderly process for determining health care decision makers in the event the patient is unable to communicate his or her wishes and failed to execute a valid durable power of attorney for health care, living will, advanced directives, or medical proxy.

The Attorney General proposed a 2001 legislative resolution requesting that the Department of Health proclaim that pain assessment and pain management has a positive impact on outcomes and quality of life of the patient. Therefore, a patient's pain should be assessed on a regular basis and treated appropriately.

The Attorney General proposed a 2001 legislative resolution requesting that the Department of Health proclaim the benefits of hospice care for terminally ill patients and their families.

Upcoming measures to improve end of life care:

The Attorney General's Health Care Advocate will develop a guide for health care providers concerning Rhode Island criminal law parameters for treatment of pain.

The Rhode Island Partnership on Improving End of Life Care will continue the study of end of life care in Rhode Island pursuant to the Robert Wood Johnson Foundation Grant awarded to Aging 2000 and Brown University School of Medicine.

The Health Care Advocate will work with professional organizations, such as the Rhode Island Medical Society, to support educational projects for physicians concerning pain assessment, pain management, hospice care, and the role of pastoral and spiritual care for terminally ill patients.

The Health Care Advocate and the medical community will provide outreach to the public concerning the benefits of pain management and their right to pain management under the law.

The Health Care Advocate and the medical community will educate the public concerning the services of hospice care.

The Rhode Island Medical Society, the Health Care Advocate and the Rhode Island Bar Association will develop strategies to improve communication between the patient and the provider concerning the patient's end of life care wishes and the transfer of that information between health care facilities.

The Attorney General's Medicaid Fraud Unit will participate in the educational component of pain assessment for health care providers in Medicaid facilities. This program is part of the Attorney General's ongoing commitment to vigilant enforcement of the proper standards of care for Rhode Island's nursing home patients.

RECOMMENDATIONS

The Attorney General will establish a state sponsored Task Force with representatives from health care providers, advocacy groups, academia and government. The Task Force will examine the following recommendations that resulted from the End of Life Conference Series, develop and assign responsibilities to carry them out and review the implementation process. The recommendations to be analyzed are as follows:

Health care providers should assess pain on a regular basis and treat pain because pain can affect recovery and the quality of life for the patient.

Health care providers' continuing education should include a component addressing pain assessment and management.

Policymakers, advocacy groups, physicians, nurses and nursing home administrators should educate the public about the benefits of pain management and their rights under the law regarding pain management.

Qualified medical personnel should develop indicators for quality of care for the dying, including pain assessment and management and explanation of treatment options including hospice care.

The entire medical community should encourage physicians to explain hospice care as an option for treatment for terminally ill patients. The Rhode Island Medical Society and other professional continuing medical education programs should educate physicians concerning the services of hospice care.

Advocacy groups and the medical community should work to educate the public concerning the role hospice care can provide for the terminally ill and their families.

Attorneys and the medical community should educate the public concerning the options available for expressing their wishes for end of life medical treatment when they are unable to communicate with health care providers, including the limitations of such instruments.

Advocates, attorneys and the medical community should educate agents/surrogates concerning their responsibilities as a health care agent/surrogate.

Policymakers should develop a mechanism for health care decision making in the event that a patient fails to execute a valid durable power of attorney for health care, living will, medical proxy, or advance directives.

The medical community, advocacy groups and attorneys should develop systems to improve the communication between the patient and the health care providers about health care advanced directives, durable power of attorney for health care, living wills, or medical proxies.

The medical community, advocacy groups and attorneys should work to improve the transfer of advanced directives, durable power of attorney for health care, living wills, or medical proxies between health care facilities, such as the hospital and the nursing home.

For nursing home patients, legal documents should include a provision regarding the patient's preference to be hospitalized or to remain in the nursing home, unless hospitalization is necessary for the comfort of a terminally ill patient.

Policymakers should develop a mechanism other than transferring the patient to another physician if the attending physician cannot honor the patient's request for end of life treatment.

Attorneys and the medical community should educate health care providers concerning their potential liabilities, in the event that they do not honor a valid durable power of attorney for health care, living wills, advanced directives, or medical proxies.

Advocacy groups, religious leaders, and the medical community should educate health care providers concerning the importance of providing for the pastoral and spiritual needs of terminally ill patients.

EXECUTIVE SUMMARIES

Executive Summary

IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

JOAN M. TENO, M.D., M.S.

Associate Professor, Community Health and Medicine

Center for Gerontology and Health Care Research

Brown University School of Medicine

Associate Medical Director, Hospice Care of Rhode Island

Per capita, Rhode Island has the nation's second-highest percentage of elderly residents. Rhode Island leads the nation in the number of deaths in a nursing home. Nearly two-thirds of the deaths occur in persons over 75 years of age. The majority of Rhode Islanders die of chronic illnesses, such as heart disease, cancer, and pulmonary disease.

Dying is no longer a time limited event, but rather a process of slowly failing. Almost half of those dying are in pain, often severe pain. Eight-three percent of nursing home residents experience pain that impairs mobility, causes depression, and diminishes quality of life. Pain can be managed through medication; however, one in four nursing home residents did not even have an analgesic prescribed. A recent Brown University Study found nearly 30% of nursing home residents with daily pain not receiving pain medication. Pain management needs to be improved.

Advance directives not only plan for end of life medical treatment but can also provide direction for pain management. Most nursing home residents who are dying have advance directives. Unfortunately, often the advance directives did not help in the end of life decision making process because they were too broad, not appropriate, or never reached the health care provider. Advance care planning, through medical proxy, living will, durable power of attorney for health care, or advance directives, needs to be improved so that patients' wishes can be respected.

Another area of end of life care which can affect pain management and the quality of life is pastoral counseling. Most people at the end of life do not get the pastoral counseling they needed or wanted. Although physicians are medical professionals, the impact of spiritual comfort is important to the patient and should not be forgotten when treating terminally ill patients. Patients can be referred to the religious organization to which he or she belongs.

To improve end of life care in Rhode Island, policymakers should focus on nursing homes and develop specific indicators to measure quality of care of dying patients. Pain management should be a top priority. The State of Rhode Island needs to establish a Task Force to improve end of life care which could address these issues.

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IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

KATHLEEN C. HITTNER, M. D.

President, Miriam Hospital

Anesthesiologist

Pain management includes addressing the pain itself and the effects of pain or the pain medication. In addition, other factors, such as anxiety, depression, sleep deprivation, and lack of mobility, need to be considered. The World Health Organization developed guidelines for pain assessment and treatment, but they are not used often enough by physicians. Pain should be assessed on a regular basis and treated. By evaluating pain on a regular basis, - perhaps a "Fifth Vital Sign," pain can be managed with lower concentrations of narcotics and an improved quality of life for the patient.

Narcotics can control approximately 70 to 95% of pain. Although it has been proven that only 1% of patients given narcotic medication for pain becomes addicted, doctors are hesitant to prescribe them in sufficient quantity to relieve pain, for fear of being accused of hastening death or causing addiction. Providing adequate pain medication is not the same as assisted suicide, even though narcotics can depress the respiratory system. Adequate pain management is essential to quality health care.

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IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

DAVID R. GIFFORD, M.D., MPH

Gerontologist

Clinical Coordinator, Rhode Island Quality Partners

Medical Director for Several Nursing Homes

Nursing homes have an average of 100 admissions per year, sixty-six percent of which occur at for-profit facilities. Approximately seventy-five percent of nursing home residents are women, with an average age of 84. More than fifty percent of nursing home residents are 85 years of age or older. Most nursing home residents are Caucasian. Most nursing home residents are admitted from hospitals. Over fifty percent of nursing home residents suffer from dementia, while at least eighty percent are impaired in their decision-making abilities. Almost fifty percent of nursing home residents need assistance to eat and 96% need help bathing and dressing. The nursing home population requires significant services.

The nursing home staff cares about the residents and wants to do the right thing. However, the turnover of staff is tremendous. Directors of nursing have a mean tenure of only 6-8 months. Administrators have a mean tenure of 6 months. And the most important link to patient services, certified nursing assistants ("CNAs") experience a 100% turnover in 12 months. This does not mean that every CNA changes jobs every year; it means that some CNAs change jobs several times during a 12-month period, resulting in a mean of 100% turnover. The nursing home population is vulnerable to receiving less than the care that they need or want because of the nursing home population and staffing turnover. Nursing homes are an excellent place to study end of life care and implement improvements. Some recommendations include:

- '' leverage current resources
- '' measure and report outcome
- '' change funding regulations

Rhode Island has experienced some success in helping nursing home residents express their end of life treatment wishes. Almost one-half of the people admitted to nursing homes have some form of an advance directive within the first 48 hours. These documents usually deal with "do not resuscitate" ("DNR") codes; however, often there are communication deficiencies concerning these advance directives. Communication difficulties can occur between the resident/patient and his or her family, or during transfer from and to other health care

facilities. More often than not, the communication difficulties impede the honoring of the patient's wishes for end of life care. A system to improve the transfer of durable powers of attorney for health care, advance directives, living wills, or medical proxies would benefit the patients and the health care facilities.

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IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

MARGARET S. WACKER, R.N., Ph.D., C.S.

Clinical Specialist, Pain Management

Rhode Island Hospital

To summarize the American Nurses' Association position statement on the Promotion of Comfort and the Relief of Pain in Dying Patients in two sentences:

Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient; The increasing titration of medication to achieve adequate symptom control is ethically justified.

Scientific knowledge and technology can provide adequate tools to relieve pain. Relieving pain enhances the patient's quality of life and can improve clinical outcomes. Proper pain treatment decisions need the cooperation of many medical disciplines, such as medicine, nursing and pharmacy. Certified nursing assistants provide valuable input as well. In addition, supportive services for financial resources may be needed to provide patients with adequate pain treatment. Pain medication is expensive, but it is necessary to improve the quality of the patient's life. Even if pain can be managed by the medical team and the financial obstacles overcome, the fear of law enforcement penalizing the medical profession interferes with optimal pain relief management. Health care professionals need to be able to work without the pervasive and persistent concern that the Drug Enforcement Agency is ready to restrict or revoke the licenses of health care professionals.

Executive Summary

IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

EDWARD MARTIN, M. D.

Medical Director, Hospice of Rhode Island

The hospice system provides end of life care, including pain management, emotional support, and pastoral services. Hospice focuses on improving the quality of life while you are dying. Hospice can provide care and attention on a daily basis to control symptoms, including pain. All patients with cancer or other terminal disease should have the chance to decide whether or

not to receive care from hospice. Unfortunately, many patients do not have the opportunity to avail themselves of the full range of services at hospice because the patients are not referred early enough.

Dying patients are often not referred until there is a crisis. The average time between referral to hospice and death is usually 14 days. Medicare restricts referrals to hospice care by prohibiting ongoing treatment and requiring that the patient must be within six months of death. Doctors have difficulty estimating the life expectancy of someone with a terminal illness. The physicians fear charges of health care fraud for referring a terminally ill patient too early to hospice. Ultimately, the patients lose the opportunity to receive hospice services for months or weeks while their health is declining. Health care financing rules need to be changed so that terminally ill patients can receive hospice services and physicians need not worry about prosecution.

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IMPROVING END OF LIFE CARE

PAIN MANAGEMENT

OCTOBER 25, 2000

J. JEFFREYS BANDOLA, M. D.

Private Practice

Our culture holds that a sudden, painless death is the desirable way to end a fulfilling life. Whether this may or may not be true for the deceased, it certainly is not desirable for the surviving family who will carry the wound of sudden loss through the remainder of their years. On the contrary, there is much to be said for a terminal course where all are aware of the approaching death, but the victim is offered a respite of comfort for a few weeks or months where they can take leave of their friends and family and help their survivors to accept the coming loss and memorialize the life of the loved one. This is a time of privileged communication between patient and child, husband and wife, and is not to be trivialized. My practice has allowed me to participate in many such deaths. Each is different, each family and patient express unique needs that require the full scope of my talent and training. These situations are sad, but deeply fulfilling for all involved. Well-managed terminal care is the ultimate gift we can give our patients, this in turn enriches our lives, and the lives of all who participate.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

NANCY FISHER CHUDACOFF, ESQUIRE

PRIVATE ATTORNEY

A document that an individual chooses to use to express wishes about end of life care can be called advance directives. There are two types of advance directives provided for in Rhode

Island law. One is a durable power of attorney for health care and the other is a living will. Both statutes seek to respect the patient's wishes but the living will is more limited because it can only be used by persons with a terminal condition.

The Durable Power of Attorney for Health Care Act, R.I. Gen. Laws § 23-4.10-2, allows a person to authorize an agent to make health care decisions in the event that he or she cannot. It provides directions to the agent and ultimately to health care providers about the types of treatments that the patient does or does not want. Such direction should be clear and understandable; otherwise, the health care provider will not be able to honor the patient's wishes. The duration of a durable power of attorney for health care can be open or for a set time period. A durable power of attorney for health care must be executed as set forth in the statute and signed by two witnesses who are not designated as an agent or alternate agent(s); an employee of the health care provider; the operator of a community care facility; or an employee of the operator of a community care facility. The document should be given to the designated agent and alternative agent(s), the family, the primary care physician, all health care providers, hospitals, and nursing homes.

The living will, formally known as the Rights of the Terminally Ill Act, sets forth the patient's wishes that his or her dying should not be artificially prolonged, if he or she has an incurable or irreversible condition that will cause death within a relatively short time. The living will directs the attending physician to withhold or withdraw procedures that merely prolong the dying process and are not necessary to alleviate pain and to comfort the patient. The living will also requires that two persons, who are not relatives of the declarant by either blood or marriage, witness the signature of the patient. The living will is only effective if the patient's condition is terminal, the patient is unable to make treatment decisions, the existence of the living will is communicated to the attending physician, and the attending physician determines that the patient is in a terminal condition.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

EDGAR BATSFORD, RN

EMERGENCY MEDICAL TECHNICIAN

Physicians and nurses who honor durable power of attorney for health care are protected when honoring a patient's wishes to withhold life-sustaining measures. Until 1992, Emergency Medical Technicians (EMT) did not have such immunity. Today, the Comfort One Program permits EMTs to honor a terminally ill patient's wish not to receive life prolonging treatment, provided the patient is registered in the Comfort One Program. The EMTs may provide support services, such as oxygen to help the patient feel more comfortable.

The Comfort One Program is administered by the RI Department of Health ("DOH.") A terminally ill patient may refuse life-prolonging treatment and if the patient wants the refusal to be effective for emergency medical services, the terminally ill patient must request that the attending physician registers the patient with the Comfort One Program. The physician provides the patient's name, address, and other pertinent data to DOH. DOH maintains a master list of patients who are enrolled in the Comfort One Program. The physician affixes an orange bracelet alerting EMTs to the patient's participation in the Comfort One Program.

Once a patient is enrolled in the Comfort One Program, the EMTs have the same standard of immunity for not providing life-sustaining measures as a nurse or a physician. If the patient changes his/her mind, the bracelet can be removed at any time (even in the presence of the EMTs). REMEMBER: living wills, durable powers of attorney for health care, or notes from doctors on prescription pads are not adequate notice of the patient's refusal of life-prolonging treatment for EMTs to have immunity for not providing it. Without such immunity, EMTs will and must perform life-saving procedures, even if it is against the patient's wishes. Only belonging to the Comfort One Program will give EMTs immunity for not providing life-supporting treatment and permit EMTs to honor a patient's wish not to receive life-prolonging treatment.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

THOMAS A. BLEDSOE, M.D.

CLINICAL ASSISTANT PROFESSOR, BROWN UNIVERSITY

ETHICS COMMITTEE,

RHODE ISLAND HOSPITAL

Treatment for end of life is difficult to define. Aggressive care treats the terminal condition and palliative care should be given to all patients regardless of whether they are receiving aggressive care for the underlying disease. There is also the treatment of complications of the disease and or the symptoms. These issues should be talked about with your family and physician before they occur. Respecting a patient's wishes is an attainable goal if the patient is alert and can express desires; and his or her wishes should be honored with the appropriate treatment. An incompetent patient with a legal surrogate is not so straight forward, and with no surrogate, it is even more difficult for the health care facility. When advance directives are authorized, it means people have thought about the end of life care they want and have made decisions. Empiric data shows surrogates are poor at predicting what patients want, even when they know the person well.

Hospitals are required to ask all admitted patients whether or not they have advance directives. However, after admission, the advance directives do not always accompany the patient through the hospital stay and discharge. Systems need to be implemented that will include the appropriate delivery of the advance directives to the patient's health care providers.

The Hospital Ethics Committee is a multidisciplinary group, usually made up of physicians, nurses, hospital staff, ethicists, hospital chaplains, community members and often, legal representatives. The Ethics Committee reviews end of life care issues, particularly when the patient's wishes for treatment are not known or are so loosely expressed that it is difficult to determine them. The Ethics Committee focuses on the ethical response first and then deals with the legalities. If more patients provided clear direction concerning their end of life care, fewer end of life care issues would need to be referred to the Ethics Committee.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

HONORABLE JULIUS MICHAELSON

FORMER ATTORNEY GENERAL, STATE OF RHODE ISLAND

PRIVATE PRACTICE

Rhode Island's first Durable Power of Attorney Health Care Act was passed in 1992 and the first law providing for a terminally ill patient to express his wishes to terminate life-prolonging treatment was passed in 1991. The first case in Rhode Island to decide the right to withhold life-prolonging treatment was litigated in 1988 in the U.S. District Court for the First District in Rhode Island. *Gray v. Romeo*, 697 F.Supp. 580 (D.R.I. 1988). Marcia Gray was diagnosed as being in a persistent vegetative state at the State General Hospital in Cranston. Her husband wanted the feeding tube and life support being administered to her, removed. The State General Hospital refused. The District Court concluded that court decisions support a "principle of self-determination that encompasses the right of an individual to control his or her own body..." *Id.* at 584. Moreover, "the right to control medical decisions affecting one's body is deeply rooted in our country's history and traditions." *Id.* A person has the right to refuse to eat, whether orally or through a G-tube. Therefore, the Court held that Marcia Gray could refuse to be fed by the G-tube. If the State General Hospital refused to comply with her wishes, then it must transfer her to a facility that will honor her wishes.

Rhode Island law provides that if an attending physician or health care provider cannot honor a patient's end of life treatment wishes, then the attending physician or health care provider shall transfer the patient to another physician. R.I. Gen. Laws §§ 23-4.10-6 and 23-4.11-7. Failure to transfer the patient to another physician is a violation of the law and may result in disciplinary charges. However, filing a disciplinary complaint against the doctor with the Physicians Licensure Committee and proceeding to a hearing provides little or no comfort for the patient who continues to receive treatment to prolong his life against his wishes. What can we do to obligate the physician or the hospital to honor the patient's wishes? Suppose another physician or another hospital will not accept the transfer of the patient. The law must be changed to address these problems.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

GERALDINE A. MANCONE

AMERICAN ASSOCIATION OF RETIRED PERSONS

The American Association of Retired Persons ("AARP") is an organization for people who are 50 or older. Needless to say, improving end of life care is important to its membership. Medicine provides the technology that allows us to live longer and the law provides the mechanism for us to express our wishes for end of life care. We have come to accept a new concept in the law known as advance directives, usually a Living Will or Durable Power of Attorney for Health

Care. The use of advance directives is a positive step. Although, they may know about these documents, the general population does not fully understand or know how to use them properly. Most people are unfamiliar with the terms used and what differentiates each document. People are often uncomfortable with the topic and do not have discussions about end of life issues with their loved ones.

The AARP encourages people to make their wishes known to those who may have to make the difficult end of life decisions. We also encourage family members to start the conversations with those who may not have expressed their wishes. To help with such discussions, AARP has sponsored a book entitled "Planning for Incapacity: A Self Help Guide—Advance Directives Forms for R.I".

Even when people execute documents expressing end of life care wishes, the documents frequently do not reach health care providers, especially in an emergency. A system needs to be developed which would permit health care providers to access the documents when they are needed.

Executive Summary

IMPROVING END OF LIFE CARE

RESPECTING PATIENTS' WISHES

NOVEMBER 1, 2000

DAVID STERN

PRESIDENT, ONLINE-REGISTRIES, INC.

In Rhode Island, the Durable Powers of Attorney for Health Care Act permits a person to designate an agent, and, if desired, alternate(s), to be contacted in the event the individual (principal) becomes incapacitated and unable to communicate his or her wishes. What happens if the agent or alternative agent(s) are not available? How will health care providers know what your wishes are for end of life treatment? In the Internet environment in which we live, one's end of life care wishes can be available to health care providers instantaneously.

Recently, online-registries, inc. launched medicalproxy.com, which offers Internet registry of healthcare proxy information. The site securely stores medical proxy or medical power of attorney information for real-time access by accredited hospitals. The information includes the name and contact information for medical proxy agent(s), whether the principal is an organ donor and whether the principal has made special provisions regarding treatment. In the event a registrant should become incapacitated and unable to participate in treatment decisions, the data is available to be transmitted over the Internet for immediate use by medical facilities accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). All information is maintained in an "super-secure™" environment, providing the highest degree of trust available for online transmission of this data.

Executive Summary

IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

DAN W. BROCK, Ph.D.

BIOETHESIST

BROWN UNIVERSITY

Our understanding of the ethical issues and of ethically acceptable practice in end of life care has changed remarkably over the last three decades. In 1970, end of life care discussions concerned whether life-sustaining treatment could be stopped once it had been started, even though it had been decided that the patient did not have to start it. Thus, many thought there was an ethically and legally important difference between not starting and stopping life sustaining treatment. It was also acknowledged by many that terminally ill patients could stop at least some forms of life sustaining treatment, but it was widely questioned whether non-terminally ill patients had the same rights. And of course if we gave important weight to whether a patient was terminally ill, then we had to define terminal illness. There was also great uncertainty about which treatment could be permissibly foregone by patients. For example, many said that while extraordinary measures could be permissibly foregone by patients or by their surrogates, ordinary care was obligatory. And again if we were to give important ethical and/or legal weight to this distinction between ordinary and extraordinary care, then it was important to clarify how one determined which care was ordinary and which extraordinary. And finally there was great uncertainty about how to proceed when the patient was him or herself incompetent to make decisions about his or her own care. Who should be making decisions in the incompetent patient's stead, and how should that surrogate decision-maker make decisions for the incompetent patient? The authority of surrogates to make decisions about life sustaining treatment for incompetent patients was uncertain and controversial.

Over the last thirty years, most of these issues have been resolved because of intense discussion between the public and health care professionals. The courts have addressed it and professional organizations have issued guidelines. In the President's Commission Report we argued that there were two central values at stake in and underlying health care decision making. The first was that decision making about treatment should always seek to promote the patient's well being, but recognizing that life support does not always benefit the patient in modern medicine. Sometimes patients do reasonably judge that the best life possible for them with further life sustaining treatment would be worse than no further life at all, and this is the judgment they essentially make when they decide to refuse further life sustaining treatment. The other central value at stake in health care treatment decision making is respecting individual patients' self-determination or autonomy. By self-determination, I mean simply the interest of ordinary persons in making important decisions about their lives for themselves and according to their own conception of a good life, not according to someone else's idea of what would be best for them. Reflecting these values, the current consensus about treatment decision-making end of life care is that competent patients have the right to refuse any treatment, including any life sustaining treatment. They also have the right to select from among available alternative treatments, according to their own values and their own assessments of the benefits and burdens of the different alternatives.

People have gained more control over their care at the end of life, but there still are issues that need to be discussed. First, is the bias toward life, which is often employed in decision-making when the patient's wishes are uncertain. The second issue is how to make advance care planning for later incompetence more effective. A third concerns what is called futile care, whether there is any obligation for professionals to provide care they judge to be futile when patients, or more commonly, their families demand it. During this century, considerable time will be spent discussing and addressing these issues.

Executive Summary

IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

PETER A. HOLLMANN, M.D.

MEDICAL DIRECTOR

BLUE CROSS AND BLUE SHIELD OF RHODE ISLAND

Thirty percent (30%) of all Medicare expenditures paid for care for beneficiaries in their last year of life and nearly half of those were in the last thirty days of life. These proportions have remained stable over many years. It is undeniable that large sums of money are spent on people in their last year or years of life. It is logical to believe that most people who die are sick first. Often, they are chronically ill. The manner in which health care expenditures are made changes significantly with age. Those beneficiaries ages 65-74 have expenses mostly for doctors and hospitals, while those beneficiaries over age 85 spend mostly for nursing homes. Only about 5% of Medicare dollars are spent on high cost cases, representing prolonged intensive care. However, the number of patients who die after such treatment is equal to the number of patients who live. Thus, critical care is effective. For these reasons, money spent in the last year of life is not easily reduced.

The facts are clear: long-term care meets basic human needs, acute care restores comfort and function during flare-ups of chronic illness, and hospice care is essential and not free. End of life care is an essential, yet an expensive, part of medical treatment. Much of end of life expenses are quite rational. Remember, advance directives do not save money. Advanced directives may shift some expenses. Not only should the elderly be the focus of communicating end of life treatment wishes, young people should also prepare end of life treatment documents. Attention should be focused on improving the effectiveness of the doctor-patient relationship.

Executive Summary

IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

HERBERT RAKATANSKY, M.D.

CHAIR OF AMA COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

End of life care raises numerous ethical issues. However, physicians can be guided by the American Medical Association ethical guidelines. There are basic assumptions that the American Medical Association has adopted:

Physicians should not intentionally harm their patients. Competent adults have the right to determine their own destiny. In the context of the medical treatment model, competent adults have the right to sufficient information about their condition and the treatment options to make an informed decision about the treatment. Individuals have the right to refuse treatment under all circumstances.

Additionally, there are several empirical observations which must be considered in this equation to define right and wrong:

Human judgment is fallible. Death may be postponed for a while but is inevitable for everyone. From these principles, a physician can fashion his guide to end of life treatment.

The most important issues to emerge in recent times indicate that doctors do not have sufficient knowledge about the sophisticated techniques of end of life care. Since medical knowledge is an ever-changing target and since doctors have an obligation to continue their education, we can conclude that continuing education in this area is essential. The AMA has sponsored the project to Educate Physicians on End of Life Care (EPEC), which is a total curriculum for end of life care treatment for physicians. Many doctors are neither competent nor trained to deal with this aspect of end of life care. Studies have documented that narcotic medications are often prescribed in inadequate doses, both in acute self-limited illnesses and in end of life situations.

We can also conclude that there is a duty to alleviate pain and suffering during the terminal phase of life, and of course, it is also right to do this at other times of life. It is recognized that pain and suffering are not just physical but also emotional pain. More requests for physician assisted suicides are the result of emotional and psychosocial issues than from pure physical pain. I would suggest that when adequate treatment for psychosocial problems has been provided, the requests for physician assisted suicides would not continue. In the end, the doctor must judge whether end of life treatment was adequate and available and whether to honor a request for assisted suicide. I do not have faith in the infallibility of such a judgment. How can one person's judgment be reliable? Doctors should not be the arbiters and enablers for suicide.

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IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

RUSSELL SOLLITTO, J.D.

ASSISTANT ATTORNEY GENERAL

DEPARTMENT OF ATTORNEY GENERAL

The critical element to determine if providing medication to a patient is criminal is whether or not the intent of the medication giver was to cause or hasten death. Narcotic medication frequently depresses the respiratory system which, therefore, can compromise a patient's health. If the medications were given with the intent to relieve pain, then there is no criminal intent, regardless of the effect on the respiratory system. On the other hand, if the medications were given with the intent to hasten death, then criminal intent would be present. A physician must use reasonable judgment in prescribing drugs to patients in pain. Physicians should document the diagnosis and treatment in the patient's medical record. Rhode Island laws permit health care providers to treat pain and other conditions, without fear of prosecution, provided the intent is to treat and not to hasten death or shorten life. No health care provider has been prosecuted under Rhode Island law for providing pain medication when the intent was to relieve pain and not to hasten death. There are gray areas in criminal law, not everything is black and white; therefore, health care providers should protect themselves with proper documentation.

Executive Summary

IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

E. PAUL GRIMM, ESQ.

PRIVATE PRACTICE

Excluding suicide, all courts recognize a patient's right to die. If the right to die is indeed a legally cognizable right, it logically follows that the loss of that right is compensable. The doctrine which embraces the compensation anticipated by the loss of the right to die, has been labeled "wrongful prolongation of life." When a medical professional negligently or intentionally disregards the express wishes of a patient, the harm inflicted may give rise to monetary damages. The test for this type of liability is whether the unwanted prolongation of life would not have occurred but for the conduct of the medical professional.

Generally speaking, a hospital will not be liable for general damages resulting from a negligent failure to honor a patient's wishes in this area, but may be liable for other special damages, such as medical expenses. The courts have recognized a "duty to accede to a patient's express refusal of medical treatment." Such duty arises out of a patient's constitutionally valid right to die and to refuse treatment. Because of the difficulty in measuring general damages for a "wrongful prolongation of life", however, courts have been reluctant to award them.

This is by no means the only area of potential malpractice liability with regard to "end-of-life" care. The wishes of the family, as well as the patient's need for pain management and other palliative care, must be considered. Case law suggests health care providers should develop policies and procedures to handle requests to turn off life support and honor other "end of life" patient requests. Presently, there are very few cases on this subject, but it is a developing area of law. Thus, there are no clear rules yet in this area of medical malpractice.

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IMPROVING END OF LIFE CARE

END OF LIFE: RIGHT OR WRONG

NOVEMBER 8, 2000

REVEREND DOCTOR DAVID A. AMES

CLINICAL ASSISTANT PROFESSOR, COMMUNITY HEALTH AND MEDICINE

BROWN UNIVERSITY

CHAPLAIN, BROWN UNIVERSITY

An overview of the spiritual needs of the dying was presented, including the desire to live a meaningful life, to die an appropriate and pain-free death, and to find hope beyond the grave. Dr. Ned Cassem, Chief of Psychiatry at MGH, was cited for concerns raised with patients experiencing life-threatening disease. These questions include: How do you live ill? Do you

have a Faith in God or a power beyond yourself? Are you part of a Community of Believers? What sort of person is God? Qualities: compassionate, caring merciful, forgiving; or judgmental, vengeful, angry, punitive? What is communication like with God and others? What about doubt? What doubts do you have? What is God's position on your illness? How do you view death? Is there anything after death?

Physicians normally are not well trained in end-of-life planning. They are often reluctant to refer to hospital chaplains or to ask about pastoral support for their patients. Sometimes concerns are addressed with family members at the time patient has been referred to palliative care. There is a need for further education of physicians and medical students and collaboration with chaplains, nurses, and pastoral care providers.

The Brown University School of Medicine does not have a required curriculum in dying and death. There have been some isolated attempts over the years to address this topic in a few elective courses: a mini course on "The American Way of Dying;" and a number of Affinity Group Programs on such themes as Pain Control, Terminal Illness, Hospice Care, and Geriatrics and Palliative Care. These efforts are due to interests of faculty or in response to student requests. In their anatomy class, students do some writing about their cadavers; and they have gathered to discuss some of their personal and emotional responses to this laboratory experience. Medical students also hold memorial services in honor of, and in thanksgiving for, those patients who donated their bodies for medical education. Some attention is given to the process of dying and how to handle the death of a patient in third-year clerkships, but these programs are not coordinated nor are they consistent in what they teach. Part of the reason for this is that physicians who teach in clerkships and residency programs often have little or no training themselves in this area, nor do they have time or support in reflection and processing their own grief when a patient is diagnosed as terminal or when a patient dies. The approach to end of life issues at Brown University School of Medicine is not different from other medical schools. See J.A. Billings & A.S. Block, Palliative Care in Undergraduate Medical Education. Status Report and Future Directions, 278(9) Journal of the American Medical Association 733-8 (Sept. 3, 1998).

One of the first things we should be doing is to make physicians and medical students aware of the current interest in some candid discussion about dying and death among American citizens. I would begin the discussion by asking them to consider three questions: How are you going to die? How do you want to die? How do you fear that you will die?

The Park Ridge Center Bulletin reported in its March 1998 issue that, "After several decades of bearing witness to the indignities sometimes associated with high-tech death, Americans have begun to insist that dying is more than a clinical event." According to George Gallup, "The American people want to reclaim and reassert the spiritual dimensions of dying." The Gallup survey explored three clusters of attitudes and behaviors: "1) how people find comfort in their dying days; 2) things that worry people when they think about their own death; and 3) how people plan for disability or death, including the possibility of physician-assisted suicide."

"The study suggests that medical education should prepare physicians to engage the human, spiritual dimensions of the dying process as well as its clinical realities; and, overall, to understand and integrate the spiritual beliefs that so often guide their patients." An additional step should include participation in inter-disciplinary teams trained to provide for the physical comfort and spiritual support of those nearing the end of life.

Several years ago, a New Yorker cartoon illustrated this issue by showing a man's body lying in a bed and nearby a woman on the telephone. The caption read, "Tell the doctor we quite understand, if he'll just send the death certificate, we'll fill it out ourselves." Dying is a problem because, for medicine, disease is the enemy, and so is death. However, we mortals must sooner or later deal with death. We usually confront our own morality for the first time when a parent, sibling, or spouse dies, or when we are hit with a potentially life-threatening illness. Very few of us (28%) have signed any kind of legal document that designates

someone to make medical decisions on our behalf when we can no longer make them for ourselves, or that describes the type of care we would want if we can no longer recover to an acceptable degree of human function. Even fewer of us (15%) have informed a lawyer or medical professional about these concerns.

If we provide a social climate that attends to the pastoral and spiritual needs of patients, and do not hesitate from asking the difficult questions about our own mortality, I believe we can greatly enhance physicians' abilities in relating to patients during their final weeks and days of life. Perhaps we need to reclaim that older ideal of medical practice prior to the advent of our ever-burgeoning technology, "To cure, sometimes; to help, often; to comfort, always."

Local resources for end of life care

Aging 2000 - One Richmond Square, Providence, Rhode Island; (401) 521-7930 or (888) 684-7200

Rhode Island Department of Attorney General – 150 South Main Street, Providence, Rhode Island 02903; Consumer Division (401) 274-4400

Rhode Island Department of Elderly Affairs – 160 Pine Street, Providence, Rhode Island; (401) 222-2880 or (800) 322-2880

Mental Health Association of Rhode Island's Grief and Loss Collaborative – 500 Prospect Street, Pawtucket, Rhode Island; (401) 726-2285

Respite Care Services – 83 Stewart Street, Providence, Rhode Island; (401) 421-7886 or (800) 445-2033

Hospice of Kent County VNA – 51 Health Lane, Warwick, Rhode Island; (401) 737-6050

Hospice of Nursing Placement – 339 Angell Street, Providence, Rhode Island; (401) 453-4544

Hospice Care of Rhode Island – Central Office, 169 George Street, Pawtucket, Rhode Island; (401) 444-9070 or (800) 338-6555

The Borden-Carey Building – Island Office c/o Newport Hospital, 11 Friendship Street, Newport, Rhode Island; (401) 845-1606

Philip Hulitar Inpatient Center – 50 Maude Street, Providence, Rhode Island; (401) 351-5570

South County Office – 143 Main Street, Wakefield, Rhode Island; (401) 444-9010

Hospice of VNS of Greater Rhode Island – 6 Blackstone Valley Place, Suite 515, Lincoln, Rhode Island; (401) 769-5670 or (800) 696-7991

Hospice of VNA of Rhode Island – 157 Waterman Street, Providence, Rhode Island; (401) 444-9400

Northwest Hospice – 185 Putnam Pike, Harmony, Rhode Island; (401) 949-2600

VNS of Newport and Bristol Counties Hopice – 1184 East Main Road, Portsmouth, Rhode Island; (401) 682-2100

Rhode Island Bar Association's Legal Information and Referral Service for the Elderly – 115 Cedar Street, Providence, Rhode Island; (401) 521-5040

Rhode Island Legal Services – 56 Pine Street, Providence, Rhode Island; (401) 274-2652

Rhode Island Department of Health, Division of Facilities Regulation – (401) 222-2566 or www.health.state.ri.us/hsr/facreg/

AIDS Project Rhode Island – 232 West Exchange Street, Providence, Rhode Island; (401) 831-5522 or (800) 726-3010 (hotline)

AIDS Care Ocean State – 18 Parkis Avenue, Providence, Rhode Island; (401) 521-3603

Alzheimer's Association, RI Chapter - 245 Waterman Street, Providence, Rhode Island; (401) 421-0008, (800) 244-1428 or www.alzheimers.org

American Cancer Society – 400 Main Street, Pawtucket, Rhode Island; (800) ACS-2345 or www.cancer.org

Hope Center for Cancer Support – 297 Wickenden Street, Providence, Rhode Island; (401) 454-0404 or www.hopecenter.net

American Heart Association, RI Chapter – 275 Westminster Street, Providence, Rhode Island; (800) 242-8721 or www.americanheart.org

American Stroke Association, RI Chapter – 275 Westminster Street, Providence, Rhode Island; (888) 4STROKE, (800) 553-6321, or www.strokeassociation.org

National resources for end of life care

Choice in Dying, Inc. – 1035 30th Street, NW, Washington, D.C. 20016; (202) 338-9790 or (800) 989-WILL (9455)

Commission on Aging with Dignity – 7700 North Kendall Drive, Suite 602, Miami, Florida 33156; (888) 5WISHES (947437) or www.agingwithdignity.org

Partnership in Caring: America's Voices for the Dying – (800) 989-9455 or www.partnershipforcaring.org

Advance Medical Directives: Something to think About (Publication) – To order, contact Choice in Dying, 200 Varick Street, 10th Floor, New York, New York 10014-4810; (800) 989-WILL (9455)

Shape Your Health Care Future with Health Care Advance Directives (Publication) – To order, call (800) 424-2277 or write AARP-AD, P. O. Box 51040, Washington, D.C. 20091

Special Thanks To:

The Brown University School of Medicine

Rhode Island Medical Society

Rhode Island State Nurses Association

Rhode Island Bar Association

Rhode Island Department of Elderly Affairs

Aging 2000

American Association for Retired People